SOCIAL REPRESENTATIONS ABOUT AIDS IN PEOPLE OVER 50, INFECTED BY HIV[1]

Marislei Brasileiro[2]
Maria Imaculada de Fátima Freitas[3]

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This study analyzes representations about AIDS in nine persons older than 50, infected by HIV. The analysis revealed representations: 'AIDS is a constant death threat'. These were categorized and named by means of the interviewers' statements: ´No doctor thinks, at first, that we can have aids; AIDS isn't cancer; to be old and have AIDS is to be discriminated twice. The results show the importance of integral care delivery by health services to decrease the psychosocial suffering of these people.

DESCRIPTORS: adult health; nursing; acquired immunodeficiency syndrome

REPRESENTACIONES SOCIALES SOBRE AIDS DE PERSONAS ARRIBA DE LOS 50 AÑOS, INFECTADAS POR EL HIV

Este trabajo analiza las representaciones sobre AIDS de 9 personas arriba de los 50 años, infectadas por el HIV. Del análisis surgieron representaciones: 'AIDS es una amenaza constante de muerte'. Estas fueron categorizadas y normalizadas por las palabras de los entrevistados: 'Médico ningún piensa, primero, que nosotros podemos tener aids'; 'AIDS no es cáncer'; 'Ser viejo y estar con AIDS es ser doblemente discriminado'. El análisis mostró la importancia de la integralidad de los cuidados por los servicios de la salud para disminuir el sufrimiento psicosocial de las personas.

DESCRIPTORES: salud del adulto; enfermería; síndrome de inmunodeficiencia adquirida

REPRESENTAÇÕES SOCIAIS SOBRE AIDS DE PESSOAS ACIMA DE 50 ANOS DE IDADE, INFECTADAS PELO HIV

Neste trabalho, analisa-se as representações sobre AIDSde 9 pessoas acima de 50 anos, infectadas pelo HIV. Da análise, surgiram representações: 'AIDSé uma ameaça constante de morte'. Essas foram categorizadas e nomeadas pelas falas dos entrevistados: 'médico nenhum pensa, primeiro, que a gente pode ter AIDS'; 'AIDS não é câncer'; 'ser velho e estar com AIDSé ser duplamente discriminado'. Os resultados mostram a importância da integralidade dos cuidados pelos serviços de saúde para diminuir o sofrimento psicossocial dessas pessoas.

DESCRITORES: saúde do adulto; enfermagem; síndrome de imunodeficiência adquirida

[1] Article extracted from the Master's thesis; [2] MSc. in Nursing, Coordinator of Nursing course at Universidade Paulista, Faculty member at Goiás Catholic University, e-mail: marislei@cultura.com.br; [3] PhD. in Education Sciences, Adjunct Professor, Minas Gerais Federal University School of Nursing, e-mail: peninha@enf.ufmg.br

INTRODUCTION

Reaching advanced age is no longer a privilege for the few. However, concerns are not related to longevity, which many people experience nowadays, but to a good quality of life, aspired by many but enjoyed by few people.

In this search for a better quality of life, the Statute of the Elderly establishes a social policy to value aged people in Brazil. Health, education, law and social science researchers are increasingly interested in different questions about old age, including issues related to HIV/Aids prevention and control.

The National Policy of the Elderly was established on 11/04/94 by Law No. 8.842, and regulated by decree No. 1948, issued on July 03rd 1996, with a view to attending to this part of the population. Some campaigns to prevent Aids in elderly people have been organized, in line with Chapter IV - Article 10, aimed at guaranteeing that the elderly population receives health care in different care levels of the Single Health System, besides preventing, promoting, protecting and recovering these people's health, through programs and prophylactic measures[1].

In view of technological and health care advances, elderly people live a new reality in this period of their lives, which they never experienced before. However, when infected by HIV, people over 50 with low education levels tend to manifest the effects of immunodepression more rapidly than younger people as, besides Aids, they are affected by other diseases that frequently appear when old age gets closer. These effects are even more serious in people aged 65 or older.

Moreover, there is disinformation, prejudices and health service access difficulties. This probably contributes to the increase of HIV/Aids cases. Besides, there is the subnotification of cases and the fact that the epidemic is affecting individuals with lower education levels. The researchers observe these factors in their daily work, dealing with questions related to Adult and Elderly Health in health service practice. Besides these general questions, the risk of HIV infection is denied in this group, by health service users as well as by professionals attending the elderly[2].

In a recent study, physicians from the University of Chicago Hospital reported, for example, that "many professionals who deliver care to elderly persons do not manage to associate Aids with aged persons, as the issue of risk perception does not exist when looking at this population "[3].

In the absence of vaccines and an actual cure for the syndrome, and despite the increasing number of Aids patients over 50[4], there is a lack of systemized knowledge about this group, mainly in terms of quality of life and coping with the disease, including these people's representations about the event of HIV in their lives.

This kind of studies can contribute to discussions about the rights of people over 50, in order to improve their health service access and support the development of HIV/Aids prevention actions, especially in the Family Health Program.

Thus, in this study, we attempted to analyze the social representations of HIV/Aids patients older than 50, understanding how subjects with this disease represent the existence of this infection, with a view to elaborating support for new forms of prevention and infection control.

METHODS

We carried out a qualitative study, focusing on the expression of participants' subjectivity, using social representations theory. In the analysis, we sought the central and peripheral nuclei[5], for which social representations are "elements structured around a central nucleus and peripheral nuclei, to systemize knowledge in the attempt to study the object in further depth". Qualitative research extracts results like opinions, attitudes, feelings and expectations, which together constitute the social expression of the specific group under study, in a certain society and at a specific time, in short, how practices influence representations[6].

Theoretical Framework

All individuals develop in a social reality, with needs and cultural meanings that mould their values and are expressed in daily life, through social representations that are constructed in common sense, in interactions, ideologies and people's ways of life.

Based on Moscovici[8], Forgas[7] points out that the notion of social representation refers to a set of

concepts, assertions and explanations originated in daily life, in the course of communications between individuals, which are equivalent, in our society, to traditional societies' myths and systems of beliefs, which can be considered a contemporary version of common sense.

The informal conversations and the force of arguments found in the heat of afternoon discussions give "speakers" at the same time an encyclopedic competence about the discussion themes: As group conversation advances, speech gets regularized and expressions become more precise. Each participant becomes eager to transmit his/her knowledge and keep a place in the circle of attention surrounding people who are well informed. Each person obtains information and continues in the running, getting familiar with the unknown.

From the perspective of the dynamics of becoming familiarized with the non-familiar, social representations involve two processes: objectification (transformation of something abstract into something almost physical) and anchorage (fastening)[8].

In order to access these representations, the Central Nucleus Theory is proposed, elaborated on the basis of the hypothesis that the organization of a representation presents a particular characteristic: not only the elements of the representation are ranked, but all representations are organized around a central nucleus, constituted by one or more elements that give meaning to the representation. This theory suggests that the essential character of a certain representation can be discovered in further detail.

Thus, representations guide the action, that is, the way individuals look at reality determines their way of being in the world. This presupposes that ways of prevention or care after the infection are central in the subjectivity of people who experience HIV/Aids when they are over 50. This experience is loaded with beliefs and values that organize their behavior towards the disease.

In daily life, people very often only perceive the risk and severity of a disease when they are affected by it and "while there was no risk, not even of getting ill, because of the disease, the risk is now visualized as a death risk". Thus, their attitudes towards a severe illness, even if it is a pandemic, are not always accompanied by the perception that they are susceptible to infection. This sometimes leads to negligence of prevention modes.

Research subjects

We interviewed nine HIV/Aids seropositive patients who were hospitalized at a public hospital in Goiânia, Goiás, between August and December 2003. The number of interviewees had not been defined *a priori*. Two participants were 52 years old, three 60 years old and four 64 years old. The saturation of themes addressed by the patients was adopted as the criterion to interrupt data collection. The interviewees preferred to be interviewed at the institution they were hospitalized in and at the two support services for Aids patients in the state capital.

Ethical aspects

All participants received a free and informed consent term, containing information about the study and conditions for participation, in accordance with Decree 196/96 by the National Health Council[9]. None of the interviewees refused to participate. They were willing to talk about themselves, provided that their identities were protected by the use of codes for analysis and presentation of results.

Participants were informed about the research objectives and their voluntary participation, that their anonymity would be preserved and that they had the right to withdraw from the study at any time, without any pressure or harm to the care they received by health and social support services.

It should be reminded that sociological research is, in the first place, a way of systematically expressing people's views and life history. In this context, it is fundamental to deeply respect their statements, in data collection and analysis.

Information collection

Information was obtained through oral, face-to-face discourse, using open and in-depth interviews, which were audio-taped. The tapes were coded and stored by the researchers, and will be destroyed after the publication of the results.

After authorization by the Research Ethics Committee at Minas Gerais Federal University and the research institutions, data were collected at the Hospital for Tropical Diseases, at *Condomínio Solidariedade* and at the Aids Support Center in Goiânia, including patients from the state capital and nearby cities: Aparecida de Goiânia, Rio Verde, Piracanjuba, Edéia and Santa Rosa.

Information analysis

Based on the logics of the subjective trajectory[10], we attempted to deconstruct and reconstruct discourse by analyzing the narratives, in order to extract the analytic categories.

After the literal transcription of the participants' testimonies, these were read and reread on the basis of social representations theory, horizontally reading each interview. We looked for information about representations with a view to a first empirical categorization, through the themes addressed by the subjects themselves.

Soon after, all segments that coincided around a same discourse object were grouped, and each group received a provisional name, with a view to the second empirical categorization.

Based on the empirical categorization, we carried out cross-sectional reading of the interviews by organizing the contents in thematic blocks. We considered the regroupings of each interview and compared them with the conjunctions and disjunctions in the set of interviews.

In this sense, analysis involved the following steps[11-12]: close transcription of audio-taped interviews; vertical reading; elaboration of a 'paragraph' that summarizes the subject's discourse; horizontal analysis; nomination of sequences; first categorization; search for central and peripheral elements of representations according to their density in the discourse structure; elaboration of a hierarchical scheme of representations; in-depth analysis, including readings of other authors about the observed representations.

RESULTS AND DISCUSSION

The study group consisted of four heterosexual women and five men, between 52 and 65 years old. Two men presented themselves as heterosexual, while three affirmed sexual relations with men. All participants were poor and had not finished basic education.

The group included single and widowed persons, as well as people without a stable partner. Sexual exposure was predominant (eight participants), while one person believed contamination occurred through this route, but was not sure because of a history of drugs use. Hence, the group was in accordance with the epidemiological profile of Aids in Brazil, as described in Ministry of Health statistics[4], which reveal a higher number of sexually-contaminated patients. HIV can infect men and women of all ages, skin colors and social conditions, religions and nationalities. As described by epidemiology since the 1990's, sexual behavior is the main transmission route.

As to condom use, the interviewees confirmed that they did not use this before their infection by HIV.

Through these people's reports, identified in the text as E1, E2..., we attempted to discuss, in this study, how the existence of HIV/Aids is represented by the subject who has the disease. Social Representations Theory was basically chosen because of the search for the central nucleus and peripheral system, that is, of what is fixed, 'hard', but not immutable, and what is mobile and flexible and, therefore, can be changed more quickly, in representations about the disease experience. This allowed for the identification of these representations, also discussing how they are reflected in these persons' daily life[6].

The peripheral system of representations about HIV infection

- No physician thinks, at first, that we can have aids

The analysis of the interviewees' discourse points towards the existence of a representation synthesized in the following phrase: *nobody suspects that old people have it (aids) (E6)*, which seems to complicate the diagnostic definition: *I was hospitalized, then I left the hospital and I continued with the same diarrhea and loss of appetite [...] the doctor didn't find anything [...] he didn't ask anything. No physician thinks, at first, that we can have aids. (E1); I went to a doctor, I went to another one, he took an x-ray. It seems that the drug I was taking was wrong [...] They said it was herpes and that I needed to see an otorhino. That's when I went to the otorhino and he referred me to the doctor who asked the test of this thing you're saying. I stayed at the hospital for eleven days, I didn't see the test, the doctor only told me, she didn't show. I couldn't imagine either that I had it. (E7).*

The subjects' experience makes them represent the physician as the person who does not know what they have and neither refers them correctly to define the diagnosis. The patient, on the other hand, does not suppose (s)he is infected, or does not want

to imagine this. This leads to the formation of a vicious cycle, which includes the fact that the physician does not believe the elderly person can be infected with HIV and, therefore, does not immediately request the test in view of the first symptoms. Patients do not believe the physician either, because they are not attended as they would like to. Thus, without any solution to their problem, without any conditions or knowledge to solve it alone, they move towards the aggravation of symptoms, often culminating in their death.

Thus, prevention work needs to be re-elaborated constantly, which also means rethinking what is culturally constituted, seeking to move beyond the limits of simple information and constructing health education activities that are effective for professionals and the population.

- Aids is not cancer

After a shorter or longer period of despair, most people want to keep on living. Social representations about other diseases appear as a form of comparison: *You have to raise your head and continue, because this is not the end of the world, cancer is worse, 'cause it kills you suddenly, you know? (E1); At least it's not a cancer. Because this thing works like this, the doctor said that, if I take my medication as necessary, the cocktail, I won't get better, but there's a cure. I can live between ten and twenty years, now, if it were a cancer, you move and it's finished, cancer is fatal. (E7); It's not a cancer, you know, but if it were I would even be able to talk about it more easily! (E1).*

These arguments show that subjects related cancer with Aids, representing both diseases on a severity scale, probably due to the fact that Aids is a new disease, while cancer is concretized as dangerous and killing. However, we may suppose that the reference in comparison with cancer is only one way of constructing hope for their situation, based on a social imaginary, which is not that strong, making Aids more acceptable than cancer, which is a disease that 'takes away a piece' and is fatal soon after it is diagnosed (E7). Hence, this representation expresses the HIV positive persons' reaction to their contamination as a defense mechanism, by saying that there are worse situations than Aids, in this case cancer.

The comparison between Aids and cancer also appears to indicate difficulties related to the fear of being discovered and having one's sexuality disclosed. Aids entails the representation of a male homosexual disease: *In my situation (due to having sexual relations with other men), the way I live, everybody who finds out immediately starts to think bad things... (E1).*

Initially, Aids was called 'a gay cancer', about which generalized fear was created, mainly due to the fact that being infected meant showing one's sexuality and being socially condemned. If it is a cancer, but not a 'gay cancer', it becomes easier to declare - as illustrated by E1's statement.

In this sense, we no longer hear people say that Aids is 'a gay cancer', but the sexual prejudice continues. Homoerotic affective-sexual possibilities are still described as disease, anomaly, neurosis, perversion, etc. This wanting or unwantingly creates serious moral problems for many individuals with this kind of sexual option, which will affect the way they react towards HIV infection, seeking to hide their life situations.

The nuclei closest to the center

These representations are part of the more peripheral system, presented above, and preserve the age-related specificity, but are based on the same aspects as representations about aids in the general population.

- Being old and having aids means being discriminated twice

Nobody wants me anymore, nobody wants to come close to me. Everybody who saw me said: 'look at that: he has HIV!' One shows it to the other, you know? It was like that at first and, now, I don't care at all... (E2); After I took the test, the prejudice came: my family discovered, all of the neighbors discovered [...] Stupid people! [...] Then, they already started to discriminate against me, to cast me aside (E1). Now that I'm old, even more, who will want to be close to me? (E4). This shows that interactions related to the existence of HIV infection are more based on suspicion and closure than on confidence and disclosure. Aids is a threat of solitude and isolation, as the interviewees frequently indicate the need for affective and material support from family and friends and the time they most need these, but without any certainty that this will actually occur.

When they start the aging process, people fear and experience social forms of discrimination, which is aggravated by knowing about the infection

by HIV, bringing along the social representations about the disease and being confronted with discriminatory attitudes based on them. As to existing or imaginary discrimination, "non-acceptability is largely dictated by those practices that differ from and, therefore, subvert the *status quo*. Social representations that construct the 'other' as an aberration entail consequences for practice. They allow this 'other' to be mistreated and discriminated against: the subordination of these people, whose value systems, practices and identities are different, becomes a mere fair development of a law that is considered 'natural'."

The prejudice they experience and the fear of being exposed to it are present in the interviewees' discourse when they refer, for example, to the labor world, in an accentuated way. They consider the disease as yet another impediment to work, in view of the risk of being discriminated against at work as well: *The people working there will say: 'not me, he's going to contaminate me. (E1); I have this disease and the prejudice is very big. I work, but my contract is temporary, if they discover, tomorrow or after they can fire me and then how am I going to survive at this age, with this disease and without working? It's not easy. (E5).*

However, the interviewees want to feel useful and productive, capable of sustaining themselves, but feel diminished, and the disease turns their precarious socioeconomic conditions even more problematic. If we consider that many HIV patients today do not have any type of professional specialization, like in the case of the interviewees, one does not have to be pessimistic to affirm that misery only tends to increase among these patients.

People are expected to be able to retire over time, but there are many difficulties for this to happen, mainly considering the precarious nature of many participants' professional activities. What ends up existing, in fact, is the possibility of retirement because of their age only or, due to the disease, the possibility of invalidity retirement, which most interviewees liked, but before getting severely ill, since they do not gain enough money to sustain themselves, nor are there any perspectives of getting a job.

In a broader sense, retirement in Brazil is no longer the mark of people who were no longer able to perform a productive job. Nowadays, many retired people face, on the one hand, the loss of social roles, which they do not always manage to adapt to and, on the other, a society that maintains the image of elderly people as very vulnerable, even if this is not true. However, we can affirm, based on the analysis of the interviews, that participants are highly vulnerable in socioeconomic terms, increased by aids and its social representations, as stated by one of the interviewees: *being old and having aids is being twice discriminated against. (E3).*

The central nucleus

The most central nucleus is considered the strictest one, which gradually established itself over time and through the strengthening of information passed by means of daily conversations and countless social interactions. This nucleus is considered to be the hardest one to move and the least accessible to information campaigns. For subjects over 50, the central nucleus related to Aids is the disease as a constant death threat.

- Aids is a constant death threat

Aids incarnates the most recent representation of evil in the social imaginary of the West, which appears in the public space as an announced death. According to the author, the figures of leprosy and the plague produced two large regulatory models of evil: for the first, social exclusion and, for the second, "massive medicalization and standardization of social networks".

In the case of the interviewees in this study, recurrent expression *like if you're not strong, you can't bear it (E1), Aids is horrible, it seems like a death sentence. I think that this is a disease of this century, that it came for the worse (E4), the older we get, the closer to death, you know? With this 'thing', we think that everything moves even faster (E2)*, express the constant threat, both the idea of being a fatal disease and the insecurity about quality of life, the "come and go" that results in *decaying more and more each year (E5)*. All of this means the acute presence of a possible death in a short period of time, despite the counterpoint of using antiretrovirals and the hope of cure, in the long run.

In this sense, the interviewees indicate forms of resistance that make them bear this constant death threat, which can be synthesized into challenge, heroism or hope. A form of challenge to their own conditions; a view of heroism about themselves and the hope that science will find the cure. These three mechanisms reveal the search for quality of life in survival, fighting against the fear of death, oppression and subjugation to the incurability of Aids, which is

collectively expressed in the work of associations, support groups, non-governmental organizations and health services[13]. These participate in the improvement of patients' quality of life and can provide great contributions to the social reconstruction of representations about HIV/Aids infection.

FINAL CONSIDERATIONS

Throughout the discourse analysis, we managed to understand how the experience of HIV/Aids is difficult and complex and how many limitations on the participant subjects' family and social life are imposed. The analysis of social representations, including the identification of the peripheral system, with images further from and closer to the central nucleus, revealed that the presence of death as a constant threat concentrates all other representations about the disease and its treatment.

The full picture indicates that the life situation of people over 50 infected by HIV is based on social isolation, on the fear of being or having been discriminated against, on having been infected and moving towards old age; on the lack of work and concrete perspectives in daily life; besides difficulties to maintain treatment, mistrust towards health professionals, among others. The underlying representations found in the analysis show that much remains to be done to break with the common and imaginary sense that goes against civil rights and possibilities of a concrete improvement in these people's quality of life. This requires the elaboration of actions that are not restricted to medication treatment, but involve multiprofessional and multisector activities, which can cope with the problems experienced by infected patients and their relatives, besides individual and collective prevention policies, which lead to the reconstruction of representations, removing current attitudes of rejection, prejudice and abandonment from common subjectivities.

These research results also attract attention to the importance of adequate training for health professionals to deal with HIV/aids seropositive people over 50. It is not enough to understand them in a less biological way, we need to understand what goes on in these people's imaginary, create spaces that allow for open-hearted interactions, constant follow-up and multisector support, which allow for effective and social care to people over 50 infected by HIV.

REFERENCES

1. Política Nacional do Idoso 1996, Pub. L. no. 8842, (Dec.10,1996).

2. Gorzoni M. Síndrome de imunodeficiência adquirida em pacientes acima de 50 anos de idade internados em um hospital Geral. Folha Médica 1997 novembro/dezembro; 107 (5/6): 191- 4.

3. Dixon O. AIDSin the third age. [homepage on the Internet]. Estados Unidos: [updated 1997 Jul 27; cited 2000 Jul 10]. Available from: http://www.third age.com./features/healthy/Aids/12678.html

4. Ministério da Saúde (BR). Secretaria de Vigilância à Saúde. Programa Nacional de DST e Aids. Bol Epidemiol no. 1. 26a. semana janeiro-junho 2004; 17:3-28.

5. Abric JC. Abordagem estrutural das representações sociais. In: Moreira ASP, Oliveira DC, organizadoras. Estudos interdisciplinares de representação social. 2a. ed. Goiânia (GO): AB; 2000.

6. Sá CP. Núcleo central das representações sociais. Petrópolis (RJ): Vozes; 1996.

7. Forgas J. Social cognition: Perspectives ond everyday understanding. In: Schulze CN, organizador. Novas contribuições para a teorização e pesquisa em representação social. Coletâneas da ANPEPP 1996 setembro; 1(10):17.

8. Moscovici S. Representação Social da Psicanálise. Rio de Janeiro (RJ): Zahar; 1978.

9. Ministério da Saúde (BR). Diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Brasília (DF): Ministério da Saúde; 1997.

10. Dubar C. Trajetórias sociais e formas identitárias: esclarecimentos conceituais e metodológicos. Educação e Sociedade 1998 setembro-dezembro; 19(62):1-14.

11. Freitas MIF, Ferreira DN, Lauar H, Bonolo PF, Guimarães MDC. Adesão ao tratamento antiretroviral de pessoas infectadas pelo HIV: uma abordagem qualitativa. 7o. Congresso Brasileiro de Saúde Coletiva; 2003. outubro 6-7; Brasília, Distrito Federal; 2003.

12. Demazière D, Dubar C. Analyser les entretiens biographiques: l'exemple de récits d'insertion. Paris (France): Nathan; 1997.

13. Brasileiro EM. O sexo nosso de cada dia. Goiânia (GO): AB Editora; 2000.

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